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Young people with type 1 diabetes and their transition from paediatric to adult services: the role of community nurses

Abstract

More than 85% of our children and young people with type 1 diabetes are not achieving the recommended target of <7.5% HbA1c and are at risk of developing long-term complications. The delivery of care, including the transition process, is a potential contributory factor towards such poor outcomes. The emphasis needs to be on joint multi-disciplinary working across all health sectors, including primary and secondary care, in order to ensure that young people receive the right support. This has important implications for the community nurse who needs to take a more active role in the transition to adult services for young people with type 1, especially given the emphasis on long-term condition care in the community. This article focuses on the results of a research study that examined the transition of young people with type 1 and looks at the role of community nurses in young people's diabetes care.

Key words: type 1 diabetes; transition; young people; community nurses

Background

The UK has the fourth largest population of children and young people with type 1 diabetes in Europe and the fifth largest population in the world (Kanavos, 2011; Diamond Project Group, 2006). At present there is no comprehensive, standardised approach to care in paediatric or adult services, nor in secondary or primary care. Over the past decade, UK standards and guidelines (Department of Health (DH), 2001, 2007; National Institute for Health and Clinical Excellence (NICE), 2004) have specifically focused on children and young people with diabetes, and substantial improvements within services have been achieved (Gosden et al, 2010). However, evidence from the recent National Diabetes Paediatric Audit (NDPA) Report (NDPA, 2011) shows that more than 85% of children and

young people with diabetes did not achieve the NICE recommended target of <7.5% HbA1c; this has remained unchanged over the past 7 years. In the recently published Atlas of Variation in Healthcare for Children and Young People (DH, 2012), the delivery of care given to children and young people and their families is highlighted as a potential contributory factor towards such poor outcomes. Therefore, by ascertaining the current standards of care and the gaps in service and by acting on recommendations to improve diabetes care, it may be possible to eliminate this as a contributory factor towards poor outcomes. However, in order to gain a true picture of current services, and in particular the delivery of care, it is important that service provision is looked at from the point of view of all those using and involved with the service, including children and young people, their parents and healthcare professionals.

A research project has recently been completed and launched at the annual Diabetes UK Professional Conference specifically involving young people with type 1 diabetes, their parents and health care professionals. The aim of this was to ascertain the current state of diabetes care provision for all children and young people up to 25 years of age and the steps that needed to be taken to improve the service. A key aspect of care that was highlighted as an area of concern was transition, along with the lack of continuity and co-ordination in the care of young people with diabetes.

Transition is defined as the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems” (Blum et al, 1993). In most research studies it is widely accepted that the transition process should respond to the needs of the individual young person and, therefore, has to be participative, flexible and supportive (Brooks et al, 2009). Equally important is the concept that all professionals who have contact with young people with long-term health conditions, including those with type 1 diabetes, should be aware of the significance of the transition process, especially in terms of young people’s health outcomes. The Royal College of Nursing (DH, 2004) along with the Department of Health (2006; 2008) emphasise that joint multi-disciplinary working is essential across all health sectors, including

primary and secondary care, in order to ensure that young people receive the right support. This has important implications for the community nurse where it is becoming increasingly incumbent on such professionals to take a more active role in the transition to adult services for young people, especially given the emphasis on long-term condition care in the community and empowering young people to self-manage. Even though most transitional care models to date are not primary care focused (McDonagh, 2007), the potential for community nurses to be involved in the transition process is becoming more widely recognised, not least because of the continuity in care that they can provide. Currently, community nurses are already involved in the support of young people with type 1 diabetes and other long-term conditions where they are attached to a community or rural hospital. In addition, some primary care organisations are developing specific initiatives for young people with long-term conditions who are frequent users of hospital services that involve community practitioners (DH, 2006).

This paper reports on the transition process and the role of community nurses in young people's diabetes care (Allen et al, 2010).

Methods

A three-year, multi-site research study, 'Join Us On Our Journey', was commissioned by NHS Diabetes to examine the current situation in Yorkshire and the Humber, with the emphasis being on the delivery of care. Nine acute trusts across the region, involving over 300 participants, took part. Process mapping was employed as the main methodology incorporating three broad, overarching questions:

1. What is currently happening?
2. What is missing?
3. What needs to happen?

The rationale behind using the process mapping approach was to map out the type 1 diabetes journey from diagnosis through to transition. This meant establishing what worked

well, what worked less well, where the areas of inefficiency were to be found and how a particular area needed to improve. Talking groups (a term coined by the young people to describe focus groups) were used to generate discussions with groups of children and young people, parents and professionals about their perceptions, beliefs and attitudes in relation to diabetes care provision.

Key topics, closely aligned to the policy document, 'Making Every Young Person with Diabetes Matter' (DoH, 2007), and including transition, represented the main points for discussion. A written and verbal explanation to the study was given, informed consent obtained and confidentiality assured. The talking groups were recorded with the participants' consent and appropriate ethical and research governance approval was obtained. Data analysis was undertaken by members of the research team using thematic analysis. Research participants verified the themes and established the reliability of the research findings.

Results

The research findings presented here relate to transition and young people's diabetes care. Additional research findings are reported elsewhere (Kime and Carlin, 2012).

A growing body of research demonstrates that transitional care is often inadequate, focused on service transfer rather than a holistic process centred on the individual (Visentin et al, 2006; Kirk, 2008). This research served to further reinforce this concept and highlighted transition as a major area of concern for those involved. There were huge inconsistencies in transitional care across the various diabetes teams. Transition differed in each trust, in terms of the length of the process and the age at which a young person moved through transition. Although it was regarded as a vital time in respect of a young person's diabetes journey and was known to have important implications for the ways in which young people continued to manage their condition, the transition process was often poorly handled. Young people and parents stated that too much was assumed by the diabetes teams regarding their knowledge of transition. They felt that more communication was needed between paediatric and adult

diabetes services regarding young people's individual needs. For example, when participants were in transition they were often unaware of what was happening and why,

"I was originally told that because I was 13, I would be slowly put into the adult clinic but I'd spend half of my time in pediatrics and half of my time in adults to get me used to swapping over but that never happened. I didn't know I was in a transition clinic" (young person, aged, 22).

Those young people who had been through transition thought the time spent in transition was important. Ideally, they believed a year or more was appropriate for the transition process. This enabled the young person to spend time with the paediatric and adult diabetes teams and therefore, build up a comfortable rapport. Normally, diabetes services started the transition process at around 16 years of age, with transition lasting approximately 2 years and young people moving up into adult services at 18. Transition usually involved young people attending six transition clinics over the 2-year period at which both the paediatric and adult diabetes teams were present, including consultants, diabetes nurse specialists and, where possible, dietitians. None of the transition clinics included a member from the primary care team, even though the young person's GP was often the first and most immediate point of contact when illnesses developed. In most trusts, at the end of the 2-year transition period there was a formal handover to minimise confusion and to ensure that the young person and their parents were clear about which service was responsible for managing their care. Some diabetes services had a key worker, namely a paediatric nurse, who was responsible for overseeing and managing the transition process.

One major concern was the difference in record-keeping between the paediatric and adult diabetes services, both within the same trust and between different trusts. There were various combinations for recording patient information, ranging from paediatric and adult diabetes teams within the same trust using different computer systems to one diabetes team using a paper system and the other a computer-based system, both within the same trust.

Consequently, this had important implications for the handover process and the continuity, or lack of continuity, of care,

“... we could have a young person on our case load for nearly 18 years and when they move to adult services their notes don't follow so all that vital history and information is not used as both services work on different databases” (health care professional).

In addition, the system used for recording patient information in the trusts differed from that used in primary care, making communication problematic, in the sense that existing systems did not facilitate access to shared records nor the two-way exchange of information.

In general, all participants who accessed the paediatric diabetes service were extremely positive about their diabetes care and commented on how helpful and supportive the diabetes teams were. In contrast, those young people who accessed the adult diabetes service were not as happy with their care and made frequent comparisons between the two services, in terms of how good their care had been in paediatric services and how poor their current care was in adult services. Staff attendance in clinic and lack of continuity were major issues,

“...at the children's clinic I had thorough appointments and saw doctor, nurse and dietitian. More recently, my appointments are a complete waste of time, seeing a different doctor every time for a maximum of 5 minutes...I can't remember the last time I saw a nurse or dietitian” (young person, aged 22).

Paediatric diabetes teams admitted that they nurtured their young people and 'held onto' them for longer than they should. They stated that they worried about the young people not being able to adjust easily to their new adult care regimen. In adult services the young

people were encouraged to be more independent, but the consequence of this was that clinic absence rates were higher.

Young people and parents commented on how the period of transition was a vital time in the young person's diabetes journey and, therefore, greater emphasis needed to be placed on ensuring young people and their families were assisted through the process.

Conclusion

This research is the first of its kind that has consulted with over 300 young people with type 1 diabetes, their parents and professionals to find out about young people's diabetes care provision. The findings presented here provide a snapshot of some of the key issues that are prevalent in transitional care for young people with type 1 diabetes, although the same issues are relevant for all young people with long-term health conditions who experience transition. Importantly, the findings indicate that there are significant weaknesses in the transition process. In particular, there are disparities between hospital based paediatric and adult diabetes care and very few links made with primary care services, especially those resources available in the community setting.

Whilst it is increasingly recognised that the period of transition is a vital time in a young person's diabetes journey and more is being done to assist young people and their parents through the process, a greater emphasis needs to be placed on the young person and different ways of working, beyond that of the traditional medical model of transfer from paediatric to adult services in hospitals. Strategies that encourage collaborations between primary and secondary care need to be developed further to provide optimal support for young people with diabetes and to prevent them being lost in transition at such a vulnerable stage in their diabetes journey. This is where the role of the key worker is so important. Although this is usually a nominated paediatric nurse, research demonstrates that there is scope for this role to be undertaken or supported by a community transition nurse (The Royal College of Physicians of Edinburgh Steering Group, 2008). In this role, a community

transition nurse could participate in transition clinics, helping to bridge the gap between secondary care, primary care and the home, whilst also providing the essential link in communication to support young people and families, primarily through the two-way exchange of information.

Increasingly, a holistic model of transitional care is being advocated, one that allows for the fact that young people are undergoing changes far broader than just their medical needs (Dovey-Pearce et al, 2005). This further reinforces the concept that transition should not solely be restricted to care within the hospital setting, but needs to take account of the lifestyles of young people with type 1 diabetes and their families. This means that in their day-to-day work as community nurses, professionals frequently come into contact with young people who have a long-term condition in the home setting and are, therefore, in an ideal position to oversee young people with type 1 and their diabetes management.

The research findings and wider literature both support the need for a re-design of diabetes services to improve diabetes care and outcomes for young people in transition across the UK (DCCT, 1994; EDIC, 2001; Kime and Carlin, 2012; Peyrot, 2009). The aim should be to develop an integrated framework between paediatric and adult services, and the wider community, with multi-disciplinary and multi-agency input. Therefore, community nurses with their specialist skills and experience have a necessary and important part to play in any re-configuration of transitional care for young people with type 1 diabetes.

Key points

1. Improvements in the transition process for young people with type 1 diabetes are essential to ensure continuity of care.
2. Strategies that encourage collaborations between primary and secondary care are needed to provide optimal support for young people with type 1 diabetes.
3. The role of the community nurse is important in the re-configuration of transitional care for young people with type 1 diabetes.

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